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Patients who challenge[☆]

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Individuals have different values. They seek to express their individuality even when receiving medical care. It is a part of modern medical practice and respect for patient autonomy to show respect for different values. We give an account of what it means to respect different values and challenging patients in medical practice. Challenging choices are often choices which are perceived by many to be either irrational or against a person's interests, such as engaging in harmful or excessively risky activities. When the medical profession is involved in such choices, the basic medical principle of acting in a person's best interests is challenged. Often doctors refuse to respect controversial choices on paternalistic grounds. We should all respect and facilitate the controversial choices of competent individuals, subject to resource limitations, our own and others well-being and autonomy, and the public interest. But more importantly, sometimes such choices make for a better, more autonomous life. Sometimes, such choices reflect considerations of global well-being or altruism, or idiosyncratic attitudes to risk. Sometimes, they reflect unusual values. However, in some other cases, controversial choices are irrational and are not expressions of our autonomy. Doctors should assist patients to make rational if individual choices. The patient also bears the responsibility for bringing his beliefs to the attention of the clinician.

Key words: ethics; autonomy; paternalism; refusal of treatment; patient values; patient choice; best interests.

[☆] Parts of these arguments appear in Savulescu J., *Controversial Choices* in Rhodes R, Blackwell Guide to Medical Ethics. Forthcoming 2007.

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INTRODUCTION

All clinicians will be familiar with the clinical challenge presented to the anaesthetic skills of the practitioner by patients suffering from significant medical conditions. This chapter deals with different challenges which may be in addition to those or in isolation and which arise from other demands made upon the anaesthetist or intensivist as a result of religious or other firmly held beliefs, or other pressures which impact on the clinician. These other stresses could affect the normal clinical practice of that clinician, the care provided or the attitude to that care. Some of these pressures are avoidable; some are present but may be unrecognised. This chapter will attempt to highlight some of these pressures and how they can be understood, approached and managed both ethically and clinically.

Many patients look to their anaesthetist not only to provide them with a pain free peri operative period, but also to act as their representative or advocate during the surgical or intensive care period when they are unable to communicate their own wishes.¹ In order to carry out this occasionally arduous responsibility the anaesthetic profession needs to be aware of the various requirements that such minority groups may have, how strongly held these beliefs and desires may be and wherever possible to understand the thinking behind their wishes.

GENERAL PRINCIPLES

Patient values

Individuals have different values. They prioritise their values in different ways. Patients who challenge make choices which are perceived by many to be either irrational or against a person's interests, such as engaging in harmful or excessively risky activities. When the medical profession is involved in such choices, the basic medical principle of acting in a person's best interests is challenged. Often doctors refuse to respect controversial choices on paternalistic grounds. We should all respect and facilitate the patients who challenge and the choices of competent individuals, subject to resource limitations, our own and others well-being and autonomy, and the public interest. But more importantly, sometimes such choices make for a better, more autonomous life. Sometimes, such choices reflect considerations of global well-being or altruism, or idiosyncratic attitudes to risk. Sometimes, they reflect religious or unusual values. However, in some other cases, controversial choices are irrational and are not expressions of our autonomy.

Case Example 1. Amputation for apotemnophilia

A Scottish surgeon, Mr Robert Smith, amputated the healthy legs of two patients suffering from apotemnophilia, a body dysmorphic disorder in which the patient feels incomplete with four limbs. The patients had received psychiatric and psychological treatment prior to the operation, but had failed to respond to these methods. Both operations were carried out privately and not publicly funded, and the patients were satisfied with the results. The NHS Trust responsible for the hospital banned further amputations.²

Case Example 2. Requests for "Futile" Medical Treatment

Mr Leslie Burke was 45 years old.³ He had been diagnosed in 1982 with cerebellar ataxia, a degenerative brain disease.⁴ He was wheelchair-bound and his speech was

affected⁴, though his mental capacity was intact.⁴ Due to the progressive nature of Mr Burke's disease, he would require artificial nutrition and hydration at some point. He sought a court ruling that such treatment be provided if he became incompetent. Mr Burke sought a declaration that the rights enunciated in Articles 2,3,8 and 14 of the European Convention on Human Rights pursuant to the Human Rights Act 1998 (UK) were breached by the General Medical Council's guidance entitled, 'Withholding and Withdrawing Life-Prolonging Treatments: Good Practice in Decision-Making'.⁵

Justice Munby ruled in favour of Mr Burke,⁶ and declared that parts of the Guidance were unlawful, as a competent person pursuant to Articles 3⁷ and 8, is able to demand artificial nutrition and hydration in accordance with the rights of dignity and autonomy which enable a person to die in a manner in accordance with their desires.⁸

However, the decision was appealed.⁹ The Court of Appeal ruled that Justice Munby erred in law. The Court of Appeal found that the Guidance was lawful and that it did not contravene Articles 2,3 or 8 of the Convention and set aside the six declarations¹⁰ made by Munby.

Challenges

Patients may challenge their doctors in 5 ways:

1. Refusal of standard/beneficial medical treatment
 - a. Refusal of life saving blood transfusion or other religiously proscribed substances
 - b. Refusal of life-saving Caesarean section for obstructed labour
2. Requests for non-standard medical treatment eg interventions with significant risk for the purposes of enhancement of normal features or to take account of non-health related values
 - a. Cosmetic surgery
 - b. Requests for "futile" medical care — artificial ventilation, artificial nutrition and hydration when permanently unconscious
 - c. Requests for modified treatment to take account of religious or other values.
3. Insisting on liberty to engage in risky activities and denying personal responsibility or engaging in activities where arguably the risk outweighs the benefit
 - a. Gastric stapling for obesity
 - b. Participation in risky research for money
 - c. Smoking
 - d. Drug taking (alcohol, heroin, ecstasy, etc)
 - e. Non-compliance
 - f. Live Organ Donation, e.g. donating one of two healthy kidneys
 - g. Assisted Suicide and Euthanasia
4. By making demands on Special Relationship
 - a. Friends and Relatives
 - b. Private Patients
 - c. High Profile Patients
5. Presenting a Risk to the Doctor
 - a. Highly infectious disease- CJD, influenza, SARS, HIV
 - b. Physical threat to the doctor

Ethical principles: respect for autonomy

The importance of consent in law derives from the ethical importance of respecting people's autonomy in liberal democracies.¹¹ The word, "autonomy", comes from the Greek: *autos* (self) and *nomos* (rule or law).¹² Respect for autonomy captures the value that people should be the authors of their own lives, free to construct their own conception of the good life and act upon it. Importantly, being autonomous does not merely involving being competent and making a choice — it involves constructing a concept of how one's life should go according to a coherent set of values. Some choices frustrate or undermine our deepest values and autonomy. Thus, even though legally patients can refuse treatment on any grounds, however irrational, there are compelling ethical arguments to suggest that the exercise of full autonomy requires some element of rationality in addition to those elements of information and understanding identified by the courts.^{13,14} These arguments are based on the concept of self-determination. The idea of self-determination is not mere choice but an evaluative choice of which of the available courses of actions is better or best. The reason that information is important is to enable an understanding of the true nature of the actions in question and their consequences; but if information is important, so too is a degree of at least rationality to draw correct inferences from these facts and to fully appreciate the options on offer.¹⁴

In upholding maximally autonomous choices, we should therefore distinguish between two kinds of true imprudence:

1. Rational imprudence

Rational imprudence is imprudence based on a proper and rational appreciation of all the relevant information. Some other reason grounds the reason for action besides prudence — this is typically the welfare of others. Thus we should respect decisions to donate organs or participate in risky research, if these are based on a proper appreciation of the facts.

2. Irrational imprudence

Irrational imprudence is imprudence where there are no good reasons to engage in the imprudent behaviour. The explanation might be that the person is not thinking clearly about information at hand or holds mistaken values or wildly inaccurate estimates of risk. We should attempt to reason with and try to dissuade competent people from making irrationally imprudent choices.

The appropriate response to irrational imprudence is not paternalism but an attempt to not merely provide information but facilitate the proper reasoning about that information. More importantly it may require challenging a person's values and the reasons for hold those values.¹⁵ While patients are entitled to have whatever values they choose, including religious values, it is important to evaluate whether choices really are consonant with those values and in extreme cases, whether those values survive rational challenge.

Children and choices

It is clear that doctors must act in incompetent children's best interests, based on a plausible and defensible account of those interests, even when those interests diverge from parental values.^{16–21}

Limits on choice

There are limits on the exercise of autonomy, whether prudent or imprudent, rational or irrational.

I. Distributive justice

Distributive justice requires that our limited medical resources be allocated fairly.^{22–24} Doctors can legitimately disconnect a person who has a very poor prognosis from a ventilator, even though that patient was expecting a miracle, if a better prognosis patient requires the ventilator. The cost of providing artificial nutrition and hydration, and the use of those resources for other patients with better quality of life, provides a reason to withhold life prolonging artificial nutrition and hydration.

2. Harm to others

According to the father of liberalism, John Stuart Mill, two “maxims” determine the limits of State interference in individual action:

“The maxims are, first, that the individual is not accountable to society for his actions, in so far as these concern the interests of no person but himself. Advice, instruction, persuasion, and avoidance by other people if thought necessary by them for their own good, are the only measures by which society can justifiably express its dislike or disapprobation of his conduct. Secondly, that for such actions as are prejudicial to the interests of others, the individual is accountable, and may be subjected either to social or legal punishment, if society is of opinion that the one or the other is requisite for its protection.”²⁵

Harm to others may take many forms. The psychological harm to the physician of performing euthanasia is one reason against it. The increasing of a tendency to violence by refusing to take some medication or by taking some drug are strong reasons for coercion.

There have been many cases where pregnant women have been incarcerated for engaging in behaviour dangerous to their fetus. Some competent women have been forced to undergo Caesarean sections for the sake of their fetus. Such decisions have been widely criticised on the basis of a woman’s right to control her own body and the lower moral status which a fetus has in law.^{26–31} However, where a fetus will survive in a damaged state, there is a reason to intervene in dangerous maternal behaviour not for the sake of saving the foetus’s life, but on the basis of preventing harm to a future individual (Savulescu, J., *Future People, Involuntary Medical Treatment in Pregnancy and the Duty of Easy Rescue*. Utilitas. Forthcoming).

Freedom and liberal society

It is essential to constructing one’s own “original existence”, as Mill described it, that one enjoy freedom. Some plans require the assistance of others. Insofar as those plans do not harm others or unjustly consume resources, there is a reason to respect such plans. Respect for autonomy requires as much. If a doctor is willing to help a person execute even an irrational plan, there is no reason to interfere except on grounds of distributive justice or harm to others.

SPECIFIC EXAMPLES

I. Religious Values

Many religions provide guidance to their followers on aspects of what constitutes a healthy or moral lifestyle and derived from these precepts some groups have developed complex laws which include what may or may not be ingested. Some rules may be regarded as so significant by adherents that they will allow these rules to interfere with mainstream medical practice and even put their lives at risk. How a doctor, whether from the same or a different faith group, is to deal with this conflict will often

result in significant ethical dilemmas for the practitioner, other clinical attendants, the patients or their relatives.

Some adherents to religious groups may have taboos regarding their care being provided by persons of the opposite sex. Where such sensitivity is commonly found in a minority group in a local area provision should be made by the Hospital Authority providing care so that the matter can be addressed simply and without fuss. On occasions or in an emergency it may be impossible to provide a carer of the appropriate sex, and this must be made clear to the patient and their relatives and any options, if they exist, clarified for them.

During certain periods of the year fasting is common and during a fast period patients may request that no drugs which could be thought of foods should be used. Such a case was described by Krishna in 2003³² who describes a strict Hindu patient admitted for a day case procedure during a fast period who insisted that the drugs she was to be given should not come from any animal source, including egg.

Whilst the use of drugs which contain animal products are clearly undesirable to people of some faith based groups (see examples below), the use of other therapeutic agents must not be forgotten. Examples are: Intravenous fluids used to expand the circulation (*Haemaccel*, *Gelofusin*), suture materials such as *catgut* (which is in fact derived from lamb intestine and not cat), some 'natural' adhesives such as those used for colostomy bags, allogenic skin graft material derived from Pig skin, allogenic heart valves of porcine origin, allogenic vein grafts of bovine ureteric origin. Consideration must also be made to strongly held views based on faith grounds regarding the use of human graft material.

In the following descriptions of individual religions and the effect on the medical care and decisions affecting their followers we have chosen to describe the mainstream philosophy as widely practiced by adherents, but it is important to remember that individuals may interpret the guidance in many ways. When dealing with each patient who claims to be a follower of one of these groups a one-on-one discussion of the patient's personally held views must be carried out as it could differ significantly, one way or another, from the generally recognised stated position for observers of that faith group.

Jehovah's witnesses

The world wide population of Jehovah's Witnesses was recently estimated at in excess of 6.5 million in 235 countries, with about 150,000 in Great Britain and Ireland.³³ It is a Christian organisation first established in the North-eastern USA some 120 years ago and which in the mid 1940s expressed the view that followers should not receive allogenic blood transfusion. There are a number of explanations for this prohibition, the most popular and widely accepted being that this accords with the biblical injunction to refrain from the consumption of blood.³⁴ Current interpretation also adds that the Jehovah's Witnesses believe that the individual's life is represented by their blood whose consumption would be abhorrent. Whatever the explanation, it is a deeply held core value and has been extended by some to include not just whole blood but any blood product or agent derived from any blood product: examples are vaccinations and inoculations.

In recent years the increasing awareness of the risks of blood transfusion (disease transmission and mismatch) has resulted in a higher threshold for the medical profession to administer blood, and this has been cited as further support for the avoidance of transfusion.

For some the belief is so deeply held that they would rather succumb to a life threatening illness or injury rather than receive a potentially life saving blood transfusion. Clearly in the case of a competent patient who refuses consent to a blood transfusion, administration would be against the law and such action could result in prosecution. Many Jehovah's Witnesses make a legally binding Advance Directive in order to forestall any possibility of such treatment being given once they lapse into an unconscious state or lose their capacity.

Case Example 3:

A 52 year old male with upper GI bleeding is admitted to the emergency department in a poor condition with borderline hypotension and signs of incipient circulatory failure. He refuses blood or blood products on religious grounds and states that he is a Jehovah's Witness. He carries a properly executed advanced directive. His wife accompanies him. She is not a devout Jehovah's Witness and begs the attending medical staff to ignore his wishes and treat him with blood. During the resuscitation period senior members of the patient's congregation visit and support the patient's refusal to accept transfusion.

The attending medical staff use non- blood products to raise the circulating volume to allow the patient to be counselled about the risks he runs, including the likelihood of death. In spite of the aggressive volume replacement and other pharmacological support bleeding continues and the patient is referred for emergency surgery in an attempt to control the bleeding. During surgery the patient goes into cardiac arrest from which he cannot be resuscitated.

Discussion:

The patient has expressed a view whilst competent and made arrangements for this view to be represented in the event he becomes incompetent. He has refused to give consent to a possibly life saving therapy against the advice of his doctors. As a competent adult he has the legal right to refuse such treatment as he wishes and the doctors must respect that wish even if they cannot agree with it.

Many otherwise law-abiding physicians express the view that once the patient is anaesthetised they would administer the blood transfusion necessary to maintain life and not tell the patient afterwards in the belief that 'what the patient doesn't know won't hurt them'. This is wrong and would destroy patient confidence in their medical attendant in addition to placing the physician at risk of professional, criminal and legal proceedings.³⁵

Case Example 4:

A 5 year old is admitted following a Motor Vehicle Collision with intra-abdominal bleeding from a splenic tear whose parents refuse blood transfusion as they are both devout Jehovah's witnesses. The risks to the child's life are explained but the parents are adamant that they will not permit transfusion but consent to surgery. In the opinion of the medical attendants, surgery without transfusion is likely to be unsuccessful so following explanation to the family present of the procedure they intend to follow, they request the hospital management urgently instruct the Trust's solicitor to seek a Court order to permit transfusion. The child is taken to theatre for an emergency laparotomy.

Discussion:

Surgery for intra-abdominal bleeding could be successful if the haemorrhage can be rapidly controlled and if the facilities for auto transfusion of washed red cells exist. The

use of the 'Cell-saver' may be acceptable to a Jehovah's Witness when transfusion of allogenic donor blood is not, and this should be checked at the preoperative consultation. The cell-saver transfusion may abolish the need for a transfusion entirely or delay it until the Court order is available. If the situation were to become so serious that death was imminent before the court order was available it is the view of the Association of Anaesthetists of Great Britain and Ireland that all lifesaving treatment should be given irrespective of the parents' wishes, with the expectation that courts are likely to uphold the decision of the doctors who give blood.³⁶

Case Example 5:

A 15 year old with liver trauma whose parents refuse blood transfusion is admitted with signs of increasing blood loss. His parents are notified and they attend but as practicing Jehovah's Witnesses they refuse to consent to transfusion. The teenager is conscious and alert and expresses the view that he does not wish to die and that the doctors should go ahead and do whatever they need to, including transfusion. The Medical Attendants ignore the parental refusal, gain the patients Consent signature and proceed to surgery.

Discussion:

In England and Wales young adults of sound mind from 16–18 years of age have a statutory right to consent on their own account. It is often prudent to seek parental consent also but the patient's consent will take precedence over parental objections. (In Scotland and Ireland the legal age for consent is 16 years). In England and Wales children younger than 16 who can demonstrate they understand the proposed treatment and consequences of their actions, either to accept or refuse treatment, may be regarded as competent. (known as Gillick-competence). This capacity is unlikely to apply below the age of 12 years. [See Chapter 2 Informing and Consenting for Anaesthesia. A Aitkenhead.]

There may well be side effects of accepting limitations on treatment such as the refusal to receive a blood transfusion. Such consequences, e.g. increased surgical time, increased high dependency admission, use of expensive or limited availability treatments (hyperbaric oxygen therapy) or drugs (erythropoietin) may increase unit costs or decrease general availability as a result of a non clinical request and this may have a limiting effect on other patients.

Jewish patients

According to the 2001 Census for England and Wales³⁷ there are 250,000 Jews of which only a small percentage would describe themselves as Orthodox. The Jewish dietary laws (*kashrut*) are complex, but are generally understood to prohibit the consumption of any food or other substances derived from certain prohibited animals (commonly pig), fish (commonly all shellfish) and birds (any bird of prey) but also that even permitted foods must be prepared in a particular way to become 'kosher' (i.e. suitable for consumption).

Judaism maintains a pragmatic approach to health and regards the continuation of life as its highest priority so that any conflict between the health of the patient or any medical provision for its maintenance and strict Jewish law is generally decided in favour of the health of the adherent. Where choice exists between a pharmaceutical or other therapeutic preparation derived from a prohibited source and one derived from an acceptable one, the default should clearly be against the prohibited. If no alternative

exists to the prohibited and the patient would suffer without the treatment then the treatment should be administered.³⁸

Case Example 6:

A 65 year old orthodox Jewish patient is admitted for total hip replacement. During surgery under general anaesthesia he suffers a medium blood loss not sufficient to trigger a blood transfusion. He had requested the avoidance wherever possible of animal products during the procedure. Volume replacement is with crystalloid avoiding the unit protocol fluid which is derived from gelatin of animal origin.

Hindu patients

There are 500,000 Hindus in England and Wales.³⁷ For the majority of Hindus, bovine meat products or derivatives should not be consumed in any form. In the Hindu tradition, cows are venerated, but not worshipped.³⁹ Even those Hindus who consume meat or animal products will usually refrain from using anything of bovine origin such as leather but milk and dairy products may be permitted. Therefore it would be better to use products that do not contain any ingredients of bovine origin while administering medication to Hindus: as far as possible alternative products should be used.

If there are no other substitutes available, and particularly if the circumstances are life-threatening, it would be best to inform the patients or their relatives of the contents of the drug and seek their permission before administering it.⁴⁰

Jain patients

There are 25,000 people in the UK who stated they were of the Jain Faith in 2001.⁴¹ Jain aim to treat each and every living beings as equally precious, and therefore avoid the killing of any creature (including animals, birds, fish, and even insects) wherever possible. All drugs and therapeutic agents containing substances derived from non plant based living organisms should be avoided.

Islamic patients

There are about 1.5 million adherents of Islam in England and Wales.³⁷ A large proportion of these will follow Islamic dietary laws which regard the pig as an unclean animal and which have strict rules regarding the killing and preparation of bovine animals (*halal*). Particular attention should be drawn to the avoidance of substances of porcine origin (e.g. Porcine Insulin, pig derived skin grafting material and Pig allogenic heart valves).

Non faith based diets

Vegetarianism

Vegetarianism is a rapidly growing dietary option in the UK. Estimates are difficult to make but according to the Vegetarian Society UK a conservative guess would be that there are in the region of 3 million vegetarians in the UK, with an increasing proportion of these being young adults. In addition many adherents of eastern religions are strict vegetarians so that this number almost certainly underestimates the total

following a vegetarian regime. Recent correspondence in *Anaesthesia* reported⁴² the lack of recognition by many western anaesthetists of the origin of many of the drugs and other therapeutic agents in use and went on to ask whether clinicians should ask all patients if they have any dietary preferences and, if appropriate, explain that many of our currently used anaesthetic agents are derived from or dissolved in substances derived from animal origin. Clearly there is a need to be familiar with the vegetarian alternatives, where they exist, so that the anaesthetic given can be as safe and skilful as the non vegetarian alternative. If the non vegetarian alternative is safer than the vegetarian is it ethical to offer the less safe option in order to satisfy a non medically imposed requirement?

Others⁴³ in the same edition of *Anaesthesia* commented on the failure of clinicians to recognise the cultural or personal sensitivity required to care for patients with special dietary requests.

The publication of this series of letters in 2005 was followed by a further response⁴⁴ from Kartha et al which questioned the financial cost and ethical basis of the use of expensive alternatives to standard drugs and therapies to satisfy non-medically induced requests from patients, and went on to suggest that there needs to be a debate to consider the demands of individuals weighed against the finite resources of the NHS. To our knowledge this debate has not yet taken place on a national scale.

Administration of a drug knowing that it contains or is derived from a prohibited source to an unwilling patient is not only arrogant but unethical, and may indeed be illegal if it can be shown that the patient had expressed his views formally regarding treatment.

Table I. List of formulations of animal origin with suggested alternatives.

Name of drug	Comment	Alternatives
Gelofusine, Haemacell, Volplex	Derived from gelatin	Hydroxyethyl starch solutions (various manufacturers)
Heparin	Contains heparin calcium of porcine origin	Unfractionated low molecular weight heparins Direct thrombin inhibitors such as argatroban (GlaxoSmithKline, Research Triangle Park, NC)
Haemoglobin-based oxygen carrier solutions such as Hemopure (Biopure, Cambridge, MA)	Bovine (purpose-bred cattle)	Allogenic blood, hypertonic solutions, perflurorcarbons
Propofol	Contains egg phosphatide	Cleofol [®] (Themis Medicare, Mumbai, India), does not contain egg phosphatide
Total parenteral nutrition solutions	Many of these preparations contain egg or animal fats	Solutions can be made using vegetarian products
Insulin	Older formulations derived from bovine and porcine origin	Human insulins (various manufacturers)
Hyaluronic acid	Contains hyalectin of avian origin	None available

This Table I is taken from Navarange, S., Rathinam, S., Makker, R. & Butler, A. (2005), *Anaesthesia for vegetarians*. *Anaesthesia* 60(5): 520–521 by the kind permission of the publishers.

Vegans, lacto vegetarians and lacto ovo vegetarians

All the comments applied to vegetarians above apply also to these other groups who avoid all product derived from animals in addition to food from dairy sources or eggs. It is also possible that some extreme Vegans would be uncomfortable with a blood transfusion because of the likelihood that the donor had not been a Vegan. This is another situation where a direct conversation with the patient could elicit their views and clarify these consent issues.

In addition some Vegans would share the views of the Animal Rights supporters and eschew all mainstream medical products on the grounds that their development had involved the use of testing the product in animals.

Responsibility to inform

Doctors should certainly respect values articulated by a patient. But how far should they go to elicit and conform to patient values? It is our belief, particularly in public medicine with its limitation in resources, especially the doctors' time, that it is the responsibility of the patient to articulate any atypical or religious values which proscribe certain practices or products. It is not the responsibility of the doctor to be familiar with each religion or divergent set of values and the implications for medical practice. Doctors have a responsibility to describe what treatments will be offered. It is the responsibility of the patient to elicit whether these conform to religious or other values. Producing accessible standardised information on commonly used products and procedures for common religious values is desirable.

Patients whose care may produce a conflict of interest

Extra pressure may be placed upon the anaesthetist who accepts or is obliged to provide care for a patient where the usual patient/clinician detachment is difficult to achieve. There may be many reasons for this extra difficulty, and some of these difficulties may differ from nationality to nationality or culture to culture.

Patients known personally

Relatives. In the UK it is regarded as unethical to provide medical care for one's immediate relatives precisely because of the difficulty of maintaining the necessary distance generally thought to be required for the provision of proper care for patients. Clearly the advice given to a close relative may be tainted by considerations of a wish to avoid pain, distress or financial penalty, which should be absent in order to give a completely balanced opinion.

In different countries the approach to the ethical dilemma of anaesthesia for close relatives may be at variance with this view and an expatriate doctor might be placed in a potentially hazardous position when the local expectation differs from his own. In Japan for example, the clinician is viewed as the most appropriate provider of medical care for his family⁴⁵ who will have such a high opinion of his skill that to be referred elsewhere would be a family insult.

Case Example 7:

The wife of a British anaesthetist working in Tokyo for a year's fellowship requires an urgent Caesarean Section for delivery of their first child. Her husband is expected to provide

anaesthesia. The husband explains to the duty team that his wife requires his presence at the head of the bed as is his custom in the UK. Whilst his Japanese colleagues do not fully understand his preference they accept his wishes and provide a senior clinician to administer the anaesthetic care.

Friends. The lay public may be unfamiliar with the technicalities of modern anaesthesia and its increasing specialisation. This may lead to the ethical dilemma whereby a close friend who holds a somewhat embellished view of the anaesthetist's abilities requests said anaesthetist to provide care in an area outside the usual specialty covered by the clinician in question.

Case Example 8:

A 75 year old friend of the family requests an anaesthetist to provide care for a complex neurosurgical procedure. The anaesthetist is NOT a practicing neuro anaesthetist and has not given a neurosurgical anaesthetic for several years. The anaesthetist explains to the patient that professional protocol guides his hand in this matter and that the neuro anaesthetist is the appropriate clinician to provide care but that he will be present as an assistant throughout the induction and/or procedure to comfort and please his friend.

Professional colleagues. If the admission of a respected or retired colleague may also result in the dilemma of whether to provide care outside one's particular area of expertise, this should be dealt with in the same way as was suggested for a family friend.

A patient colleague may wish to express a preference for another colleague who may not be on duty or the listed anaesthetist for the proposed surgery. This could be perceived as an insult and result in a conflict between the anaesthetist and his colleague.

Case Example 9:

A retired ex- colleague and department chairman is admitted with acute peritonitis. He requests the attendance of his erstwhile deputy who whilst still working has largely ceased to provide out of hours cover, in preference over the duty anaesthetist a newly appointed consultant colleague not known personally by the patient. The duty consultant contacts the requested colleague and offers to assist him in the procedure thus satisfying the wishes of the retired patient and the colleague whose skills may be somewhat out of date.

High profile patients. Whilst these patients may be known to the clinician by their position, the clinician is likely to be unknown personally to the patient. Awareness of the consequences of not living up to the highest standards of the profession may produce significant pressure on the anaesthetist's performance, but the experienced clinician should be able to draw on his experience to dissociate himself from the patient's position and treat him in the same way as any other patient. The other example given below is where an outside influence, which may or may not be linked to the patient, places external pressure on the anaesthetist.

Case Example 10:

The Prime Minister is admitted following a fall whilst attending a local party event, suffering a compound fracture of his tibia. He requires immediate surgery for application of an external fixation device before returning to the Capital. He requests spinal anaesthesia so

he can watch the procedure and remain clear headed throughout. He gives a history of previous spinal surgery for a herniated disc. The anaesthetist explains the risks of spinal anaesthesia, gives all the other options but the patient is adamant. The anaesthetic is uneventful.

Case Example 11:

The leader of a criminal gang is admitted with serious head injury which occurred during his arrest. The hospital receives an anonymous telephone threat that a poor outcome will lead to significant retribution on the surgical team! The police are informed and the surgery proceeds. Protection for the clinical team and their immediate family is provided by the police until the outcome of surgery is clear.

Non compliant patients

One of the consequences of granting adults autonomy in their lifestyle is that some make choices which are at odds with good health. Similarly some other patients, either wilfully or as a result of bad decisions choose not to follow the advice of their medical attendants. Should such patients be discriminated against where their choices have added significantly to the risks of adverse outcome associated with anaesthesia?

Drug compliance failure

For many therapies, such as antihypertensive therapy, continuation of therapy is essential to good control. Some patients are unable to follow the regimen prescribed for them through poor education, poor explanation, wilful behaviour or simple lack of thought. As a consequence the patient may be at increased risk if anaesthesia is not delayed in order for full stabilisation to be achieved. This may result in an increased risk of the presenting condition becoming more significant. Can an increased risk from the primary pathology be balanced against an increased risk from delayed treatment of the presenting condition?

Case Example 12:

A hypertensive patient on antihypertensive therapy is admitted for surgery to a newly diagnosed breast cancer. She has not taken her antihypertensive treatment regularly, but any delay in surgery could lead to the development of metastasises and a poorer outcome from surgery. Surgery must be undertaken as soon as the blood pressure levels are acceptable even when not yet optimal. The increased risk to the patient of the failure to await optimisation must be explained to the patient and her views also taken into consideration. Follow up for the hypertension must be planned to encourage future compliance.

Case Example 13:

A hypertensive patient on antihypertensive therapy admitted for surgery to repair a cruciate ligament in the knee. She is found to have been non compliant in respect of medication and the blood pressure is significantly raised. The patient has made extensive arrangements for the care during her hospital admission of her elderly parent who lives with her. She pleads with you not to cancel her operation and promises to take her medication regularly in future. You explain that any additional morbidity which could arise

peri-operatively as a result of her previous non compliance is likely to make her less able to care for her parent and that a delay in surgery to bring her hypertension back under control is in fact in her and her parents best interest. Her operation is postponed for three months, or until her pressure is well controlled and she is referred back to her GP's care.

'Non Compliance' can also encompass a group of patients who ignore general or specific health advice and therefore put their lives at risk by their behaviour.

Morbidly obese

It is widely recognised that the morbidity of anaesthesia increases with an increase above normal values of the Body Mass Index. Patients may either ignore or be unable to follow the advice of their medical attendants to reduce their calorie intake and their weight placing themselves at extra risk. The physician anaesthetist may regard the extra risk as unacceptable if the procedure is an elective one, and/or it may pose an extra stress on him/her personally if it is a non-elective one. If the physician chooses to insist on a delay he may feel that he/she is requiring the patient to undergo a further period of pain or distress in order to control their perioperative risk and that may produce stress in the clinician also.

What contribution should be made by the patient in limiting their personal rights or responsibility and how much should this limitation on their personal rights be to balance the right of the doctor to refuse treatment where he/she considers this right to be producing excess risk or stress?

Case Example 14:

A 55 year old female is awaiting total knee surgery. She has mild hypertension and Non Insulin Dependant Diabetes. Her weight is 144 kg. She is advised to lose weight prior to surgery by the surgeon and referred for preoperative assessment by the anaesthetist. At the pre-op Clinic she states that she is unable to loose weight and refuses to even contemplate it. Should she be listed for surgery at all or told that she will only be accepted for anaesthesia if she achieves a 20 kg weight loss?

Smokers

Smokers also are well recognised as having increased morbidity associated with anaesthesia. The risk of disruption of the wound, displacement of intraocular implants and increased post operative chest infections are all recognised as being increased in heavy smokers, but less positively associated in those who smoke less. Smoking cessation programmes have been successfully run in parallel with preoperative clinics in a number of centres. As with the morbidly obese patient, only a significant delay in the surgical intervention to allow for a change in habit would introduce any realistic reduction in morbidity. Nevertheless some anaesthetists see the preoperative assessment consultation as an opportunity to impart health modifying advice. Others however see this as taking advantage of a patient at a vulnerable time.

Case Example 15:

A heavy smoker aged 42 years is admitted for femoral endarterectomy for intermittent claudication of the leg. He is told that without cessation of smoking the procedure is likely to be unsuccessful in relieving the symptoms and that he will almost certainly require

amputation. The patient says that stopping smoking is impossible. Is it ethical to proceed directly to amputation?

Drug addict

Many will argue that smoking is a form of Drug Addiction, but whilst smoking appears to be on the decrease worldwide this is not the case for addiction to narcotic substances. Dependence may be emotional or psychological, but addiction generally is taken to imply that a physical dependence exists such that intense cravings are felt for the drug or its effects and that in spite of an inner knowledge that the drug is harmful intense cravings are felt and that if stopped unpleasant physical reactions occur. Drug addiction involves compulsively seeking to use a substance, regardless of the potentially negative social, psychological and physical consequences.⁴⁶ The response of the addict to counselling may not be rational.

In addition as a result of addictive habits the patient may suffer one of the blood born diseases such as Hepatitis B, or HIV and whilst this may seriously reduce the addict's ability to withstand surgery and anaesthesia can also place the attending clinicians at risk of accidental inoculation of a virus load.

Case Example 16:

A morphine addict is scheduled for surgery to an injured ankle, broken whilst escaping from the police following a break-in to a shop. The patient is not hep B+ or a HIV risk. Nevertheless he is severely cachectic and has no peripheral venous access. He is warned of future risks for own health and is offered referral to the local Addiction unit.

Alcoholic

Dependence to alcohol is common with an estimated two million sufferers in 150 countries.⁴⁷ Aside from the social disadvantages of dependence on alcohol there are also physical effects resulting from its hepatotoxicity and the neglect of diet.

Case Example 17:

54 year old male receives a liver transplant for the relief of the effects of alcoholic cirrhosis and makes a good recovery, but starts to drink again six months after hospital discharge. Routine follow up shows that he has developed alcohol induced injury in his transplanted liver but he states he is now alcohol free and wishes to be listed for another transplant if the new liver shows signs of failure. Is this appropriate?

Responsibility for illness

In theory it is true that people should internalise the costs of their behaviour. However, there are three reasons to believe that using responsibility in this way would be unfair discrimination.

Firstly, there is no way of accurately divining how responsible a person is for ill-health. Obesity has grave health consequences. It results from unhealthy eating and lack of exercise. Sexually transmitted diseases are the result of voluntary choices. It would be *arbitrary* to pick out alcoholism or smoking and not overeating or driving a car recklessly as reasons for denying a person medical care.

Secondly, the degree of responsibility for alcoholism is possibly quite low. Upbringing, peer group pressure, and perhaps genetic factors predisposing to addictive behaviour may combine to make a particular individual vulnerable to drinking. It may be that there are strong genetic tendencies to alcoholism and these same qualities may be ones that contributed to George Best becoming a brilliant footballer.

Thirdly, alcoholics and smokers contribute significantly to the National Health Service through “sin” taxes on alcohol and cigarettes, in a way that others who engage in risky behaviours do not. Smokers at least may pay their way in terms of the cost of their health care.

To start to use responsibility for illness as a way of allocating scarce resources is to descend down a slippery slope. It implies that those who contract sexually transmitted diseases like AIDS or cervical carcinoma from practising unsafe sex should not be treated. It implies that someone who breaks his neck diving drunk into shallow water should not get a breathing machine. The obese and those who eat a high fat and high salt diet should not have heart surgery. Those who engage in risky sports such as mountaineering or skiing should be given lower priority over the sedentary and docile. We should give priority to public transport users over car drivers over motor cycle riders in the allocation of scarce resources.

Political liberalism is based on giving individuals a degree of freedom to live their lives as they choose. All activities in life (especially those which are fun) entail some risk. To use responsibility for illness as a criterion for allocating medical resources would be to indirectly discourage people from engaging in activities which have risk, which may severely constrict the range of possible lives people can lead. It would be a backdoor assault on liberalism. It would also result in a very boring society.

The correct way to distribute scarce health resources like livers is through a consideration of both *need* and *expected outcome*. Alcoholics need a transplant in the same way as non-alcoholics. But we should also give consideration to the likely benefit such a transplant is going to confer. We should not waste scarce resources if they are not going to work. If an alcoholic has been abstinent and is likely to be abstinent, then a transplant is likely to be as effective in him as in a non-alcoholic. The abstinent alcoholic should receive equal treatment. However, an alcoholic who is still drinking is likely to receive less benefit from a transplant — there will be more complications and the liver will not last as long. On the basis of poorer prognosis, active drinkers or smokers (or overeaters) could be denied medical treatment. But the burden is on doctors to show that there is good evidence that the drinker will not benefit enough from a transplant to justify the surgery.

Patient with suicidal tendencies

What are the resource implications of providing significant care for patients who have attempted suicide and should concerns about the resource implications guide our treatment decisions for any cases at all?

Case Example 18:

Patient admitted with severe gunshot wounds to face and neck from suicidal attempt. He requires urgent tracheostomy and then subsequent reconstruction involving bone and soft tissue free flap reconstructive surgery to achieve even a reasonable appearance. The anticipated time for this treatment is probable a minimum of four major procedures with a total of 14 hours theatre time and several days in the post operative ITU. The unit has a significant waiting list for the treatment of urgent head and

neck cancers and it is anticipated that the use of this amount of theatre time could displace several urgent cases and significantly reduce their chances of successful cures. How much effort to resuscitate and treat this emergency should be made if it compromises other cases?

Infectious patients who pose a risk to staff e.g. HIV, Hep B or SARS

The concern at the possible inadvertent exposure of staff to risk from blood born or other highly infectious diseases has already been touched on in the question of intravenous drug abusers. During the Chinese outbreak of SARS clinicians were isolated from their families for several weeks to avoid the risk of further transmission.⁴⁸ Is the ethical discussion concerning the rights of the clinicians any different if the patient has acquired these diseases through no act on their own part but as a result of a received therapeutic blood transfusion, or other accident?

Case Example 19:

A senior clinician is required to provide care for a 48 year old patient admitted to her Intensive Care Unit with an acute respiratory failure two weeks after returning from a vacation in the Guangdong Province of China. The likely diagnosis is Severe Acute Respiratory Syndrome (SARS). She expresses concern that she may either contract the condition or transmit it to her family members. She provides the only care for her aging parents. She asks to be relieved from her clinical duties whilst the patient is in the unit.

It is unclear what level of risk clinicians can be legally compelled to assume in their duties. In general, morality requires a duty of easy rescue: that when the risk to oneself is small and the benefit of performing an act to another is great, one should perform that act. It is supererogatory, above and beyond one's moral call to duty, to help others when the risk to oneself is significant. In general, we should encourage clinicians to voluntarily assume significant risks, through compensation, praise or other means, rather than legally compelling them to treat high risk patients. In the extreme of public health emergencies, the law might be required to ensure sufficient numbers of doctors risk their lives in the public interest.

The level of risk we believe doctors should assume in their duties, applies equally to all doctors regardless of their circumstances, whether they have a family, are old or young, etc.

Patients requesting treatment for which there is no medical indication

Patients paying for surgery

Are patients who are willing to pay for their treatment entitled to expect the provision of that treatment if the clinician provider believes that the treatment itself could do harm or that its provision could have significant risks to the health of the patient? Examples are the provision of an unnecessary (i.e. unindicated) surgical procedure or extensive cosmetic surgery.

Case Example 20:

A 25 year old with a psychiatric history insists on surgery to remove minor facial scars which will almost certainly result in some scarring itself. Is the provision of anaesthesia to facilitate this procedure ethical?

Case Example 21:

A 3 month old baby is referred for anaesthesia to permit MRI for the diagnosis of possible birth trauma which if carried out will not enhance the medical care or diagnosis but which will be used by the legal representatives of the baby to support a case against the obstetrician. Is it ethical to provide anaesthesia where there is no medical indication but where the risks of the anaesthetic procedure are not insubstantial?

Case Example 22:

A 65 year old with a recent history of an acute MI demands a face lift as he wishes to marry a much younger woman. The cardiac status is fragile and unlikely to be improved by treatment. The anaesthetist explains the risks of surgery and anaesthesia but the patient says that he is prepared to go ahead at any risk. Is it ethical to proceed?

CONCLUSIONS

In essence the anaesthetist and intensivist must be aware of the rights of patients to make non clinical but challenging requests of their clinician. The patient must equally be aware that in most situations the clinician will accept these demands even when these demands place an extra burden on the clinician that could negatively affect the care which can be provided. Conversely, situations might arise, particularly in an environment with strict financial or resource limitations, when the extra burden of the challenge cannot be accepted. At all times awareness of the rights of the patient by the clinician and vice versa should lead to open and helpful dialogue in order that a mutually acceptable treatment plan can be reached.

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